# ILLINOIS HUMAN SERVICES COMMISSION

## RECOMMENDATIONS
## on
## BUDGETING FOR RESULTS,
## RATIONALIZING SERVICE DELIVERY,
## and
## REBALANCING LONG TERM CARE

January 8, 2013

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**MESSAGE TO THE GOVERNOR AND MEMBERS OF THE GENERAL ASSEMBLY**

The Executive Order creating the Human Services Commission gives it this responsibility: "recommend measures to ensure the sustainability of high quality human service delivery in the State of Illinois and make recommendations for achieving a system that will provide for the efficient and effective delivery of high quality human services."

Governor Quinn renewed the Human Services Commission for one-year term in 2012 with the charges to make recommendations for consideration by the Governor and the Legislature in the following areas:

1. Budgeting for Results
2. Rationalizing Service Delivery, including Children's Behavioral Health
3. Rebalancing Long Term Care

To fulfill this responsibility, the Human Services Commission The Commission met four times in 2012 and organized into three working committee to gather information, consult with experts and develop recommendations.

We are pleased to submit a set of recommendations contained in this report to the Governor and members of the General Assembly. The Human Services Commission hopes that the recommendations in this report will be given serious consideration by the Governor and the General Assembly.

Human Services Commission
December 19, 2012

## ACKNOWLEDGEMENTS

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We are grateful for the support and contributions made by commissioners. Commissioners provided guidance and feedback on the report through attending work group session and/or submitting written comments.

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## RECOMMENDATIONS ON BUDGETING FOR RESULTS

BACKGROUND INFORMATION

In late 2011 Governor Quinn extended the mandate of the Human Services Commission through the end of 2012 and directed it to focus on three priorities, including the role of human services in shaping Budgeting for Results. The Commission convened a work group of providers and other experts to "carefully consider the role that human services play and how these results can be measured." Our recommendations are outlined below.

### 1) Human Services Are Integral to Successfully Shaping and Implementing Budgeting for Results

Human services encompass a wide spectrum of publicly supported programs that touch multitudes of individuals and families throughout Illinois. Given the sector's large scope and numerous professional disciplines, the expertise of human services providers is a critical resource for developing and implementing a high-quality BFR system. Multiple opportunities for input should be established at every stage of the BFR process to ensure that providers and other experts contribute on-the-ground perspectives and their deep knowledge of the needs, best practices, and appropriate measurement of their services.

**RECOMMENDATIONS**

**Recommendation 1:** Revise "Result Six" of the Budgeting for Results strategic plan to clarify that BFR takes into account the full spectrum of services that impact Illinois families and is not limited to a specific set of programs for high-need populations or a specific state agency.

**Recommendation 2:** The Budgeting for Results process should ensure that each state agency provides multiple points of input from providers, other experts, and the public regarding BFR and its implementation. This input should include: information about the needs of Illinois residents; feedback on appropriate measurement of program quality and impact; development of the "return on investment" analytical model; monitoring and data collection; the elimination of redundant reporting and unnecessary administrative requirements; and periodic updates to the BFR system. This process should also be informed by relevant state managed data sources. Utilization of Application Program Interfaces (APIs) should be considered. Additional outreach may be needed to ensure stakeholders across the state have opportunities to contribute.

### 2) Ensure that Transparency and Credible Data Drive the Allocation Process

Improving services and maximizing the effective use of financial resources are at the core of Budgeting for Results. To ensure public dollars are efficiently and equitably deployed, the BFR allocation process must be highly transparent, monitored continually, and guided by credible and appropriate data about needs, costs, and best practices. The BFR Strategic Plan outlines a seven-step process, including "Step 6: Allocate Resources," which states "once evaluations are conducted and programs scored, a process must be put in place to assign funding allocations based on available resources, established priorities, and performance toward goals."

**Recommendation 3:** Clarify the BFR Strategic Plan by amending Step 6, as follows: As part of the resource allocation process, obtain and use information from community-based providers and other credible experts in program delivery to determine the funding required to obtain the results and to achieve required scale. Credible, regional data about actual costs for quality services should be used to guide funding decisions.

**Recommendation 4:** The Budgeting for Results process should explicitly recognize that full funding for high-quality services is a guiding principle for allocating state resources. In the event full funding is not available, the BFR system should make adjustments to outcome requirements and ensure these adjustments are promptly communicated to providers, consumers, and other key stakeholders.

3) **Regular Public Communication about BFR Planning and Implementation:**

Budgeting for Results must be rooted in the realities of the needs of Illinois residents, effective program delivery, and accountability in the use of public resources. Accordingly, all stakeholders -- including providers and the public -- should know how the state is progressing with BFR and have ample opportunities to participate in the process and express any concerns. Communication about BFR should focus on establishing this transparency, gathering input to create a high-quality BFR system, and encouraging authentic dialogue about the best ways to deliver services and measure results.

**Recommendation 5:** Budgeting for Results should have a clearly defined communication process that publicly reports progress on a quarterly basis. The reports should cover progress on BFR systems development, milestones, and benchmarks. The Human Services Commission should assist in disseminating BFR progress reports across the human services sector.

4) **Use Multiple Measures to Ensure the Most Vulnerable Illinoisans Are Served**

Appropriate measurement should be the watchword of Budgeting for Results. Quality measurement systems deploy a range of methods to assess specific services that may vary widely. To minimize potential negative impacts on vulnerable Illinoisans, BFR must take into account differences among programs, providers, and populations. The capacity of small providers to implement new systems varies from that of larger peers. Multiple factors must be considered to ensure the state's vulnerable residents do not become the victim of its chronic budget pressures.

**Recommendation 6:** Illinois should be cautious of attempts to monetize the outputs of publicly funded programs and services to produce "return on investment" comparisons in fields where outcomes do not lend themselves to this form of measurement. Similarly, program scoring procedures should reflect the variation of services and appropriate measurement methods in each program area. BFR should clarify how ROI calculations and program scoring procedures will be customized to distinct program areas.

The assessment and scoring of programs under Budgeting for Results should be weighted to account for the different needs and expected outcomes associated with different populations in order to ensure that assessment does not funnel investment away from programs and services aimed at the hardest to serve, which require greater investment and involve more difficult to

measure outcomes. Assessment should likewise account for the realities of service delivery, where often a successful outcome is the result of many different programs/services working in concert to provide support for individuals and families.

5) **An Integrated and Phased Approach to Implementation**

Submitting all state programs to a rigorous new process will require careful planning and broad support among many decision-makers and stakeholders. Historically, the budget priorities and proposals of state agencies, Office of Management and Budget, Governor's Office, and legislature have not always been aligned. Some providers and lawmakers have expressed concerns that a rush to put BFR in place will increase the risk of assessment errors or unrealistic administrative demands that sap resources from services. The Budgeting for Results process must help interested parties see how its priorities, outcomes, and allocations will help providers meet the needs of Illinois residents.

**Recommendation 7:** Illinois should take a phased approach to implementing BFR. This approach will allow for the thoughtful and timely realignment of expectations regarding data collection, outcome measurement, and performance, while ensuring agencies and providers establish the management capacity required by the new system. The BFR rollout process should include a fully funded capacity-building and technical assistance initiative to ensure that community-based providers are fully prepared and supported in implementing this new system. Likewise, a major focus of BFR systems design and implementation efforts should be reducing administrative redundancies, inefficient processes, and other non-service-related cost-drivers that already plague service providers. These efforts should be developed with counsel and participation from providers.

Decisions about pilots and phase-in strategies should consider the potential impact on highly vulnerable Illinoisans as different agencies and programs implement BFR. Similarly, Budgeting for Results should also be linked to a state budget process according to both need and impact. Predetermined spending caps should not be applied to the seven state budget categories in either the development of the Governor's budget proposal or the legislative appropriations process.

## RECOMMENDATIONS ON RATIONALIZING SERVICE DELIVERY; PROGRAM REORGANIZATION

BACKGROUND INFORMATION

When Governor Pat Quinn extended the Human Services Commission (HSC) in December 2011, he asked the HSC to "address delivery system issues as state agency needs warrant." To this end, the HSC created a workgroup to "rationalize the service delivery system." This workgroup has worked as two separate sub-workgroups — one focusing on improving service delivery for children with severe behavioral problems and one focusing on the location of maternal and child health (MCH) programs. The latter group has become known as the Sub-workgroup on Program Reorganization, and its recommendations are contained in this report.

*Current Location of MCH Programs*

In 1997, the Illinois Department of Human Services (DHS) was created. It absorbed the departments of Alcoholism and Substance Abuse, Mental Health and Developmental Disabilities, and Rehabilitation Services. DHS also absorbed parts of the departments of Children and Family Services (DCFS), Public Aid, and Public Health (DPH). Among the programs absorbed from DPH were MCH programs, including the Maternal and Child Health Services Block Grant (Title V), the Women, Infants, and Children (WIC) program, and Family Case Management. This basic structure put in place in 1997 remains largely unchanged.

*Governor Quinn's Proposed Reorganization*

In his budget proposal for state fiscal year 2012, which was released in February 2011, Governor Quinn proposed dissolving the DHS Division of Community Health and Prevention and moving 17 of its programs from DHS to other state agencies as follows:

- Ten programs to DPH: Healthy Families, Emergency and Transitional Housing, Targeted Intensive Prenatal Case Management, Homelessness Prevention, Family Planning, Family Planning-Title X, University of Illinois Division for Specialized Care of Children, Federal Healthy Start Program, Abstinence Education, Diabetes Prevention and Control.
- Four programs to the Department of Juvenile Justice: Comprehensive Community Youth Services, Redeploy Illinois, Unified Delinquency Prevention, Juvenile Justice Planning and Action Grants.
- Two programs to the Illinois Violence Prevention Authority: Afterschool Youth Support (Teen REACH), Sexual Assault Services.
- One program to DCFS: Homeless Youth Services.

*HSC Recommendations*

In its April 2011 report, the HSC recommended against adopting the Governor's reorganization proposal. It called for a "deliberative process to assess the appropriateness of the program changes, capacity of state agencies to absorb the changes, transition time, etc."[1] The HSC also made two sets of recommendations relating to the location and organization of programs. These included:

1. Retaining and reorganizing many DHS programs under a comprehensive "Family and Community Support Services" division. Recommended clusters within the division included Family Wellness, Child and Adolescent Health Promotion, Early Childhood Development, and Community and Positive Youth Development.

2. Suggesting the possible movement of two program clusters — Reproductive Health and Sexual & Domestic Violence — from DHS to DPH, assuming that DPH "has the capacity to absorb the programs and that appropriate transition time be developed."

When it recommended that DHS retain the programs under the new Family and Community Support Services, the HSC report noted the disagreement of the Illinois Public Health Association, which wanted all MCH programs to be transferred to DPH.

In January 2012, DHS implemented the HSC recommendations regarding a reorganization of programs within DHS and established a new Division of Family & Community Services, which encompasses programs from both Human Capital Development (e.g., child care, income assistance, and employment and training programs) and Community Health & Prevention. At the bureau-level, this reorganization aligns programs according to the rubric provided by the HSC. Within the new division, a grouping of "Reproductive & Early Childhood Services" includes the Bureau of Maternal & Infant Health. There is also a Bureau of Domestic & Sexual Violence Prevention. No programs have been shifted to other agencies.

*Impetus for Sub-workgroup Formation*

The work of this sub-workgroup was precipitated in part by the HSC's recommendation for a deliberative process to consider further program changes and in part by legislation introduced in the General Assembly by Representative Robyn Gabel (HB5363). This bill would have shifted many MCH, early childhood, and youth development programs from DHS to DPH.

*Different Views on the Location of MCH Programs*

[1] Illinois Human Services Commission, "Recommendations on FY'12 Human Services Budget and Budgeting for Results Process," April 21, 2011, pg. 9.

Participants in the sub-workgroup disagreed about the best location for MCH programs – whether these programs should remain in DHS or be transferred to DPH. Proponents of shifting MCH programs to DPH believe that the programs would benefit from having a greater "public health" focus and that this change would strengthen the state's public health system. The field of public health involves a population-based approach that focuses on the health of the overall population or community. They also noted that, unlike most other states, Illinois does not have its Title V program located within a public health agency or the public health division of a larger human services agency.

Proponents of keeping MCH programs in DHS asserted that a population-based approach is not necessarily appropriate or effective for programs that require targeting at-risk families and children. They also noted that some of these programs are designed to improve educational or developmental outcomes as well as health outcomes. There has been a considerable amount of productive effort to improve coordination between DHS and the State Board of Education. Moving programs out of DHS could weaken the coordination.

*Agreement to Focus on Future Planning Process*

While there was no consensus on where programs should be located, there was consensus on the need for a strategic planning process for maternal and child health. Participants agreed that this process should start with a clear vision for maternal and child health and desired outcomes in Illinois and then work "backwards" to determine the most effective forms of program organization to achieve this vision.

**RECOMMENDATIONS**

**Recommendation 1:** The process needs to occur as part of a group that is dedicated to making recommendations to improve maternal and child health outcomes in Illinois. This group should have clear authority from the state to carry out its work. This group should include representatives from DHS, DPH, and the Department of Healthcare and Family Services (HFS), as well as relevant service providers, advocacy groups, and other stakeholders.

**Recommendation 2:** The strategic planning process should first determine the vision, principles, and desired outcomes related to maternal and child health before considering the organization of programs. Relevant terms, such as "maternal and child health" should be defined as clearly as possible so that participants in the planning process have common frames of reference.

**Recommendation 3:** Whatever recommendations a planning group may make regarding MCH programs, it is important to have appropriate connections between data, programs, and policy. Data that are currently collected and housed in DHS, DPH, and HFS should be systematically linked with MCH programs. The group should also consider possible ways that current data systems can be improved. Finally, the group should coordinate, as appropriate, with other bodies that are examining data issues within state government.

**Recommendation 4:** Various state agencies would ultimately still have a hand in MCH programs. For example, because many MCH programs rely on Medicaid funding, HFS is a key player. Therefore, it is imperative that different agencies enhance coordination and cooperation. A planning group should pay particular attention to finding ways to enhance service integration and the continuum of care.

**Recommendation 5:** A strategic planning group should solicit input from stakeholders, paying particular attention to the needs of program clients. It is recommended that the planning group directly engage with program clients to find out more about their needs and how current programs affect them.

## RECOMMENDATIONS ON RATIONALIZING SERVICE DELIVERY; CHILDREN'S BEHAVIORAL HEALTH

BACKGROUND INFORMATION

When Governor Pat Quinn extended the Human Services Commission (HSC) in December 2011, he asked the HSC to "address delivery system issues as state agency needs warrant." To this end, the HSC created a workgroup to "rationalize the service delivery system." This workgroup has worked as two separate sub-workgroups — one focusing on the location of maternal and child health (MCH) programs and the other focusing on improving service delivery for children and youth with severe behavioral problems. The latter group has become known as the Children's Behavioral Health Sub-Workgroup, and its recommendations to the HSC are contained in this report.

The Children's Behavioral Health Sub-Workgroup has spent the past several months focusing on the system of services for at-risk children and youth with significant behavioral health problems/challenges.[2] Importantly, the Sub-Workgroup had substantial participation from leaders at key state agencies, who were engaged and very helpful at advancing the Sub-Workgroup's work. These leaders are dedicated to children's well-being and strive to deliver effective services with very limited resources and various systemic constraints. These key state agencies have specific responsibilities, programs, funding, regulatory authority, legislative mandates and regional structures and relationships related to services and supports for children and youth with severe behavioral problems.

There was general agreement among Sub-Workgroup participants that too often children and youth and their families find the current system fragmented, lacking coordination and flexibility, and difficult to access and navigate. The Sub-Workgroup's recommendations for needed improvements are based on full discussions of problems in the current system in Illinois and derived from national public policy and have been adopted by many states and localities. This policy is based on data that support a comprehensive, flexible, coordinated community-based system of services as important to good treatment and good outcomes for children and youth and their families.

SELECTED DATA

When community-based services are not adequate to maintain children and youth in their home, they can cycle in and out of psychiatric hospitalizations or stay in long-term residential placements, or in a worst case scenario, become involved in the juvenile justice system. Any out of home care, although often necessary, is expensive. Efforts to treat children and youth in their homes and communities can result in significant cost reductions as long as safety can be

[2] The encompassing term for the population of focus is "children and youth with behavioral problems," although different agencies may apply different terms. The Sub-Workgroup agrees that terms "children and youth with behavioral problems" or "children and youth with behavioral health challenges," or "children and youth with mental illness," or "children and youth with serious emotional disturbances," or "children and youth with mental health disorders" all generally describe the same population. If only "children" or "youth" is used, it still broadly refers to "children and youth."

maintained. A preliminary survey of psychiatric hospitalization and residential costs for state fiscal year 2010[3] showed:

- $149 million for acute psychiatric hospitalization paid by the Department Healthcare and Family Services (HFS);
- $200 million for residential costs for Department of Children and Family Services (DCFS) wards, which are offset by Federal Financial Participation from both Title IV-E and Medicaid;
- $17.5 million paid by ISBE for the educational costs for students in residential placements who are diagnosed as SED (Serious Emotional Disturbances); and
- $16 million for children and youth placed residentially through the Individual Care Grant Program, (ICG), which is a financial grant to assist parents/guardians to obtain residential placement or intensive community-based mental health services.

Although these figures are a combination of state and federal funds, significant General Revenue Funds are used for matching the federal funding. Because state agencies keep their cost information differently, comparisons are difficult. More in depth analysis of costs of care across agencies is a priority of the Illinois United for Youth System of Care Expansion Implementation Initiative (IUY). This group is working on gathering data on the numbers of individuals served and their cost per level of care.

There was belief among most of the Sub-Workgroup members that these costs could be lowered if a wider range of community-based services were available. These services include in-home/in-school crisis intervention, short-term community-based residential services, individualized one-on-one services such as coaching and mentoring. These services can be effective and less costly, and do not separate children and youth from the family and community.[4]

ISSUES IDENTIFIED BY SUB-WORKGROUP PARTICIPANTS

Sub-Workgroup members identified potential problems in the current system (the extent of which should be subject to further investigation and data collection), including:

- Insufficient mechanisms for effective coordination of care between levels of intensity and across service systems for children and youth their families.
- Insufficient coordination within the current treatment continuum that prevents many children and youth from accessing, and providers from being able to deliver the appropriate level of treatment in a timely way.
- Separate, inflexible funding mechanisms for programs and agencies, which effectively fragment services.
- Insufficient supports for families and a lack of family involvement in planning services for their children.

[3] State fiscal year 2010 represents July 1, 2009 through June 30, 2010.

[4] The Sub-Workgroup recognized that there are some children for whom such community-based interventions are not the best choice, but with expanded community-based interventions, this number should decrease.

- Due to the lack of access to an array of adequate services, some families are forced to relinquish custody of their children in order for the children to access mental health services.
- A fragmented administrative structure among state and local entities makes it difficult to conduct strategic planning, oversight, and review.
- Lack of a mechanism for information sharing between multiple systems involved with children and youth and their families.
- Insufficient community-based (school, home and community) services and culturally competent care planning and service delivery for children and youth with severe behavioral problems.
- Too few mental health providers available to treat children and youth with SED.
- Barriers to maximizing the use of all funding resources and taking advantage of blending, braiding, pooling and other integrated funding options to support broad benefit packages in every region of the state.
- Lack of a common database and electronic records for tracking service utilization and cost of services across systems.

It is important to note that not all Sub-Workgroup participants agreed on the degree to which the foregoing items are significant problems. However, the Sub-Workgroup wishes to capture the issues mentioned by participants that need to be subject to further study and analysis.

OPPORTUNE TIME TO MOVE FORWARD

Now is an opportune time to set about building a better system. In 2011, the Illinois legislature passed PA-96-1501, which reformed the Medicaid system. By January 1, 2015, it requires:

1. At least 50% of all Medicaid and All Kids enrollees will be in a coordinated system of care, whereby
2. Reimbursement will be made using pay-for-performance, risk-based capitation methods, thereby creating incentives for
3. Plans to improve health care outcomes, disseminate and utilize evidence-based practices, encourage meaningful use of electronic health record data, and promote innovative service models.

The requirements of Illinois' Medicaid Reform legislation focus heavily on the concept of Care Coordination – a concept that is core to Systems of Care frameworks. This overlap, or synergy, creates an opportunity to increase care coordination across the behavioral health continuum. In light of the 2012 Saving Medicaid Access and Resources Together (SMART) Act, which details 62 fiscal and administrative actions and program changes to manage Medicaid expenditures, and taken in combination with the Affordable Care Act – with its focus on integrated care and outcomes-based treatment models – the Sub-Workgroup believes that a Systems of Care Coordination Model could improve the quality of services, further reduce the utilization of inpatient and residential services, and meet the State's goals and mandates.

During the same period in 2011 and 2012, a group of cross-system agency leaders, advocates, and family members worked on a SAMHSA planning grant for statewide implementation of a system of care for children and youth with behavioral issues - the Illinois United for Youth System of Care Expansion Implementation Initiative (IUY). Since there was significant overlap of the Sub-Workgroup and IUY participants and focus, there was much collaborative work. Many of the IUY goals that build the blueprint to improve and expand services provided by systems of care for children and youth with severe behavioral problems and their families are endorsed by the Sub-Workgroup in this recommendation.

In addition, a statewide task force has been charged with developing a comprehensive five-year behavioral health strategic plan for all ages in Illinois. The actions being recommended by both the Sub-Workgroup and IUY could inform the work of the task force, specifically with regards to children's behavioral health.

## RECOMMENDATIONS

### Recommendation 1: ADOPT A "SYSTEM OF CARE" FRAMEWORK

The Children's Behavioral Health Sub-Workgroup proposes that Illinois realign the philosophy, service delivery system, organization, and financing of the public children's behavioral health service system to bring it in line with a Systems of Care framework.

By adopting a Systems of Care framework, Illinois will close system gaps and remove existing system challenges by empowering families and youth to actively engage in their own treatment needs. The Sub-Workgroup's vision of a Systems of Care philosophy involves a broad array of community-based services and supports for children and youth requiring behavioral health services. Based upon the Child and Adolescent Service System Program (CASSP) model, the Systems of Care framework provides a well-defined set of principles for the development of a behavioral health service system for children and youth *(see Appendix I)*. The Systems of Care model suggests that services be organized into a coordinated, community-based networks; build upon meaningful partnerships with families and youth; address individuals' cultural and linguistic needs; and is family-driven and youth guided. Such a model would ensure that service planning is driven by the needs and preferences of children and their families.

While placements in psychiatric hospitals and residential treatment facilities may still be appropriate for some children and youth, the Sub-Workgroup believes a coordinated community-based network based on the Systems of Care model could, in many cases, significantly reduce the frequency of admissions and expedite discharges, thus decreasing length of stay in psychiatric hospitals and residential treatment placements.[5]

[5] Sub-Workgroup members noted that the overall need for residential services may well change with an improved coordinated community-based network based on a system of care concept. For example, improving access to care could bring more children and youth into the system who need residential services, while improving "step-down" services could lead to some children and youth leaving residential care more quickly.

In order for Illinois to successfully adopt a Systems of Care framework – building the partnerships required among families, providers, community members and State agencies, and broadening its array of services – the State will need to plan for, and recognize that, the transition will be an evolutionary process, requiring time for planning, training and capacity building, and a gradual phase-in of fully working systems.

**Recommendation 2:** CREATE A SPECIFIC INITIATIVE WITHIN THE ILLINOIS CHILDREN'S MENTAL HEALTH PARTNERSHIP (ICHMP)

The Sub-Workgroup recommends that the system reform planning effort be delegated and transitioned to the ICMHP as a specific initiative with the necessary changes to their membership and bylaws to support the work.

The ICMHP[6] mandates align with the reform work being proposed, and the ICHMP's membership includes many, but not all, of the recommended leaders needed to undertake the reform work.

The Sub-Workgroup believes that, for an initiative of this magnitude and importance to succeed, there must be an entity to facilitate high-level strategic planning, oversight, review and direction with senior-level representation from state and local entities that are charged with developing and sustaining a system of care for children and youth with severe behavioral problems and related needs.

**Recommendation 3:** ROLE OF STATE AGENCIES IN FURTHER WORK

The Sub-Workgroup believes that it is important to have effective leadership and coordination among state agencies, specifically the Department of Human Services (DHS) – including the divisions of Mental Health (DMH), Developmental Disabilities and Alcoholism, and Substance Abuse – the Department of Healthcare and Family Services (HFS), DCFS, the Department of Juvenile Justice (DJJ), and ISBE.

The Sub-Workgroup further recommends that the Division of Mental Health Child and Adolescent Division be specifically charged with supporting system reform by providing leadership to a multi-system workgroup to continue the system reform planning being done by the Human Service Commission Sub-Workgroup on children's behavioral health by:

- Providing recommendations for clinical services and on the standards of care through policy development;

[6] The ICMHP, which was created statutorily through the Children's Mental Health Act of 2003, was charged with the development of a five-year Children's Mental Health Plan with yearly updates and cost savings reported to the Governor. The Act calls for this plan to contain short-term and long-term recommendations to provide comprehensive, coordinated mental health prevention, early intervention, and treatment services for children from birth through age 18. The ICMHP is also required to make recommendations in areas that align closely with the work that the Sub-Workgroup believes is needed.

- Providing guidelines for how the Child and Adolescent Mental Health System will be monitored for quality assurance consistent with Systems of Care principles and values; and
- In collaboration with HFS, convening a workgroup to develop and the process for moving towards a care coordination model for service delivery.

To carry out these tasks, it is also recommended that the Division receive adequate staffing and resource supports. As part of the multi-system workgroup to be convened by the ICMHP, the Sub-Workgroup supports including representation from families of children and youth with severe behavioral problems who are not affiliated with state agencies.

The state agencies listed above each have specific responsibilities, programs, funding, regulatory authority, legislative mandates and regional structures and relationships related to services and supports for children and youth with severe behavioral problems. The work of these agencies, as well as the work of community-based providers and funders is poorly coordinated, and no entity has a clearly defined leadership role in ensuring a seamless, coordinated system of care.

The Sub-Workgroup believes DMH should play a leading role because it is the state Mental Health Authority for the State of Illinois and is focused primarily on serious emotional disturbances and behavioral health. DMH is most informed about evidence-based practices, treatment models and systems of care for children and youth with severe behavioral problems (although DMH is not the largest funder of services for these children and youth).

**Recommendation 4:** IMPROVING CARE COORDINATION

The Sub-Workgroup recommends development of 1) a plan to research and make recommendations on standards for care coordination designed to integrate and organize services for children and youth and their families across systems, and 2) process for developing a care coordination model children and youth with serious emotional and behavioral problems.

Children and youth with severe behavioral problems often require customized care coordination approaches to meet their complex needs. They may receive treatment through the primary care system, through specialty mental health providers, and/or through other related services such as special education. Additionally, a high proportion of the children and youth with Serious Emotional Disturbances in the Medicaid population are involved with child welfare and/or juvenile justice systems. Coordination of care among these systems, together with engagement and coordination of care with the children's families, would help to improve their care and lead to better outcomes.

Children and youth with severe behavioral problems are also at high risk for co-occurring disorders, such as developmental disabilities and substance abuse, and the intensity and acuity of their needs tend to vary over time. They can benefit from a concerted (not crisis driven) care management focus, which helps to ensure appropriate care, fewer gaps in care, and lower costs as a result of earlier, more preventive and comprehensive approaches. Care coordination should

connect children and youth who have complex, multi-system behavioral health care and social needs to providers, facilitate communication among the providers, and track their care and outcomes over time. If successful, care coordination holds the potential for reducing visits to emergency rooms and hospital stays by making sure that children and youth get appropriate, coordinated treatment in the community.

**Recommendation 5:** STUDY THE ADEQUACY OF THE CURRENT SERVICE CONTINUUM

The Sub-Workgroup recommends an analysis of the current mental health treatment options and their accessibility. Further study is also needed on whether the service continuum, rules or protocols can be strengthened to provide a broad array of services and supports that are reflective of the community strengths, needs, and capacity. This would include the development of a protocol and training for providers and stakeholders to implement early intervention services consistent with current Rule 132.

Services under a system of care model should be provided in the most therapeutic and least restrictive environments, at appropriate intensity, and for the appropriate length of time based on the individual clinical needs of children and youth and their families. Within the Sub-Workgroup, there was some disagreement about the adequacy of home- and community-based services and whether the levels of utilization of psychiatric hospitalization and residential care for this population are appropriate. As part of our work, we must explore whether or not there is an adequate continuum of available and accessible services. If there is not, we should investigate possible systemic barriers there may be to establishing a more robust continuum.

Several members of the Sub-Workgroup also noted that it is essential that there be an appropriate level of care determination across systems to make sure the appropriate level of care is being utilized. It is also important that defined discharge and transition protocols are developed for discharge from hospitals and residential treatment facilities in a timely way and for movement between systems and levels of care. Participants also discussed whether, with the recent changes to the definition of "medical necessity," there is an expanded opportunity to work with children and youth earlier and perhaps without a definitive DSM IV diagnosis. Protocol development and training for providers and stakeholders might enable fuller utilization of Medicaid Rule 132 opportunities for providing services.

## Appendix I – System of Care Values and Principles[7]

### Definition

***A system of care is:*** A spectrum of effective, community-based services and supports for children and youth with or at risk for mental health or other challenges and their families, that is organized into a coordinated network, builds meaningful partnerships with families and youth, and addresses their cultural and linguistic needs, in order to help them to function better at home, in school, in the community, and throughout life.

### Core Values

***Systems of care are:***

1. Family driven and youth guided, with the strengths and needs of the child and family determining the types and mix of services and supports provided;
2. Community based, with the locus of services as well as system management resting within a supportive, adaptive infrastructure of structures, processes, and relationships at the community level; and
3. Culturally and linguistically competent, with agencies, programs, and services that reflect the cultural, racial, ethnic, and linguistic differences of the populations they serve to facilitate access to and utilization of appropriate services and supports.

### Guiding Principles

***Systems of care are designed to:***

1. Ensure availability of and access to a broad, flexible array of effective, evidence-informed, community-based services and supports for children and their families that addresses their physical, emotional, social, and educational needs, including traditional and nontraditional services as well as informal and natural supports;
2. Provide individualized services in accordance with the unique potential and needs of each child and family, guided by a strengths-based, wraparound service planning process and an individualized service plan developed in true partnership with the child and family;
3. Deliver services and supports within the least restrictive, most normative environments that are clinically appropriate;
4. Ensure that families, other caregivers, and youth are full partners in all aspects of the planning and delivery of their own services and in the policies and procedures that govern care for all children and youth in their communities, states, territories, tribes, and Nation;
5. Ensure cross-system collaboration, with linkages between child-serving agencies and programs across administrative and funding boundaries and mechanisms for system-level management, coordination, and integrated care management;
6. Provide care management or similar mechanisms to ensure that multiple services are delivered in a coordinated and therapeutic manner and that children and their families can move through the system of services in accordance with their changing needs;

[7] Excerpted from: Stroul, B. A., & Friedman, R. M. (2011). *Effective strategies for expanding the system of care approach. A* report *on the study of strategies for expanding systems of care.* Atlanta, GA: ICF Macro. Pg. 2-3.

7. Provide developmentally appropriate mental health services and supports that promote optimal social and emotional outcomes for young children and their families in their homes and community settings;
8. Provide developmentally appropriate services and supports to facilitate the transition of youth to adulthood and to the adult-service system as needed;
9. Incorporate or link with mental health promotion, prevention, and early identification and intervention to improve long-term outcomes, including mechanisms to identify problems at an earlier stage and mental health promotion and prevention activities directed at all children and adolescents;
10. Incorporate continuous accountability mechanisms to track, monitor, and manage the achievement of system of care goals; fidelity to the system of care philosophy; and quality, effectiveness, and outcomes at the system level, practice level, and child and family level;
11. Protect the rights of children, youth, and families and promote effective advocacy efforts; and
12. Provide services and supports without regard to race, religion, national origin, gender, gender expression, sexual orientation, physical disability, socioeconomic status, geography, language, immigration status, or other characteristics; services should be sensitive and responsive to these differences.

## RECOMMENDATIONS ON REBALANCING LONG TERM CARE

BACKGROUND INFORMATION

Rebalancing Long-term Care in Illinois is a broad effort by the State to provide opportunity for persons with disabilities and seniors to choose to live in appropriate, permanent, integrated settings in the community; moving out of institutional settings. Rebalancing long-term care links a number of initiatives and has profound impact on the long standing infrastructure serving the elderly and persons with disabilities. Rebalancing Long-term Care also addresses adjustment to the allocation and investment of resources from institutional to community-based care. These Rebalancing Initiatives have been driven by a combination of federal incentive programs, legal mandates based on Olmstead[i] consent decrees, long standing advocacy and best practice outcomes for persons with disabilities and the elderly, and realization of potential savings through closure of costly state facilities. Uniformly, implementation of Rebalancing efforts is based on core principles of *choice*, *maximum independence in a safe environment*, and *quality community based services for individuals*. In all instances, a successful transition will include housing and services that meet an individualized plan.

**Rebalancing Initiatives Summary Impact Chart** (additional detail provided in Appendix I)

| Initiative | Population Impacted | Facility Impacted | Geography | Est. Population | Timeline | State Agency |
|---|---|---|---|---|---|---|
| **Money Follows the Person** | MI, PhysD, DD, elderly | Skilled nursing facilities for >90 days | Statewide | Est. 3500 transitions | By 2016 | HFS; IDoA and IDHS |
| **Williams** | MI | Institutes of Mental Disease (IMD) | Chicago metro, Decatur, Kankakee, Peoria | Est. pop. 4500 | 5 yrs. | IDHS/DMH |
| **Colbert** | MI, PhysD, elderly | Skilled nursing facilities | Cook County | Est. pop. 16,000-20,000; 1100 transition in 3 yrs | 3 yrs. – cost neutral assessment | HFS; IDoA and IDHS |
| **Ligas** | DD | Intermediate Care Facilities/DD | Statewide | 100% of persons in institutional care requesting transition and 3,000 in need of services in family homes (total unserved in the community is greater) | 6 yrs. | IDHS/DD |
| **State Closures** | DD/MI | SODC/SOPH | Targeted locations | TBD | TBD | Gov. Office; IDHS/DD and DMH |

HUMAN SERVICES COMMISSION REBALANCING WORKGROUP

The Illinois Human Service Commission (HSC) was charged in December 2011, by Governor Quinn to identify strategies that "significantly expand community options" for individuals with special needs to live in community settings. The primary agenda set by the HSC Rebalancing Workgroup was to focus on recommendations 1) to enhance and build community capacity for housing and services to meet the needs of individuals moving from institutions, 2) to identify and align available resources to support Rebalancing for Long-term Care, and 3) to coordinate for positive impact on Rebalancing the managed care, Medicaid and healthcare reform efforts. The HSC Rebalancing Workgroup discussions included representatives from a large constituency of stakeholders including community service and housing providers, individual and family advocates, state agency personnel, and invested philanthropic partners. Significant discussion within the Workgroup centered on definitions and choice of living options. In the end the range of housing settings may vary, are based on choice of the individual, and are defined by the characteristics that decrease segregation of persons with disabilities, and increase options and supports that advance independence, privacy, and control over daily living for individuals.

All recommendations from the HSC Rebalancing Workgroup reflect the ***"core principles"*** identified in the Workgroup discussions:

***Choice of living options*** – *Offer and support a range of permanent housing from independent apartments to more structured or congregate settings that promote independence and community, respond to service needs, maximize the individual's abilities, and honor the individual's preferences, including those who choose to live in institutional settings. Maintain communication with individuals, families, and guardians to assure full understanding and informed choices regarding living options and community services.*

***Communication and transparency*** – *Clear communication of policies, choices, resources, and outcomes (favorable and unfavorable) will help to inform and build a stronger Long-term Care System.*

***Quality of services and settings*** – *Assure quality of available services and settings through investment in a coordinated and capable network of providers, supports, and infrastructure.*

***Maximize and align resources*** – *Identify and understand the full potential of resources and design efficient and effective systems for service delivery.*

The HSC Rebalancing Workgroup through its discussions recognized both the opportunities and challenges involved with Rebalancing Long-term Care in Illinois:

Opportunities:

- Implement meaningful system change in the quality of life and independence for persons with disabilities and elderly formerly living in institutions
- Improved transition, support, and service delivery through training and best practice studies
- Improved outcomes for individuals through coordinated case management and service delivery

- Increased access to Federal resources to leverage the State's financial investment in housing and services for persons with disabilities
- Broaden Rebalancing system changes to strengthen community care prior to moving to institutions, develop and implement individual service plans to reduce the length of stay in institutions; thereby reducing the number of individuals entering and remaining in institutional care unnecessarily
- Achieve and redistribute cost savings through reduced investment in institutional care towards enhanced housing and service capacity in community

Challenges:

- Expectations for large number of people to be transitioned over a fairly short period of time
- Complexity of needs of individuals, including varied needs between and within the targeted groups – elderly, physical disabilities, DD and MI – multiple diagnoses and complicated health issues
- The current Medicaid waiver eligibility and service delivery system is structured in "silos" based on demographics and diagnoses rather than on a coordinated system that addresses the individual's multiple needs.
- Limitations in the availability of affordable community-based housing
- General concerns that the quality and availability of care in the community will be diminished
- Need to build supports, life and socialization skills for individuals leaving institutional care to become more adept to manage responsibilities of independent living
- The current fiscal crisis in the State has resulted in reduced funding for community services and limited resources available to increase and enhance service delivery in the community
- Recent cuts to eligibility and coverage limits under Medicaid, enacted to stabilize the long term viability of the State's Program, could impact availability of services for the individuals relocating under the Rebalancing Initiatives and raise the risk of increased institutional care

The closure of State operated facilities brings about additional challenges:

- Many residents in developmental centers have lived most of their lives in similar care facilities and require significant support and skills enhancement as they transition into community living
- Potential job loss and retraining for State employees at closed facilities, and the potential negative impact on economic conditions in local communities
- Closure of psychiatric hospitals removes a significant component of the crisis care network for persons with mental illness

## RECOMMENDATIONS

Coinciding with the work of the HSC Rebalancing Workgroup, numerous other workgroups and advisory committees[ii] including State agencies, community providers, advocates, residents and families were actively engaged and generating implementation plans and recommendations on Rebalancing Long-term Care in Illinois. The HSC Rebalancing Recommendations are informed by the reports and discussions of these other workgroups. Detailed issues and actions reported from these workgroups are compiled in a series of charts in the Appendix to this report. *The Appendices I and II are provided for informational purposes and not included as part of the Recommendations presented and approved by the IL Human Service Commission.*

The HSC Rebalancing Recommendations call for and address the need for increased coordination of planning, implementation and reporting of the Rebalancing efforts.

**Build a Broader Civic and Community Consensus In Support of Rebalancing Long-term Care**

**Recommendation 1:** Develop a communication and public information campaign to build a broader community consensus on the importance of Rebalancing Long-term Care for Illinois.

The Rebalancing of Long-term Care for Illinois is a large scale effort, the success of which is based on the involvement of stakeholders at all levels of decision making. This effort encompasses numerous State and government agencies, persons with disabilities, families, guardians, advocates, leadership and staff from a broad range of community service and healthcare providers, the philanthropic community, legislators as well as new partners including, managed care companies, and private and public housing providers. Robust, current communication tools are necessary to fully inform, engage and maximize participation from a broad group of constituents, stakeholders, and the general community.

- *Develop "education and engagement forums" designed to bring Rebalancing concepts, plans, goals, and achievements to targeted audiences to expand understanding and build broader community constituency and support. Specific attention should be paid to building local municipal and business community support for housing developments, zoning, funding, community and natural support networks, and employment strategies that need community and political support, without which meeting the Rebalancing goals may not be met.*
- *Build out electronic communication tools (websites, online applications, surveys, and social media) to disseminate information, gather input, and engage in dialogue that will keep stakeholders and the general public informed on issues impacting Rebalancing.*
- *Institute broad information dissemination on current and ongoing Rebalancing outcomes to foster greater understanding and trust among stakeholders and enable learning and improvements from early experiences.*

**Comprehensive Implementation Planning for Rebalancing Long-term Care**

**Recommendation 2:** Compile a Comprehensive Rebalancing Strategic Workplan incorporating individual plans, transition goals and outcomes, strategies, financial resources, and timelines.

Currently not less than five implementation plans have been developed by State agencies and partners to meet the Rebalancing goals in Illinois. While individual plans are necessitated by court mandates and programmatic requirements, all stakeholders would benefit from a Comprehensive Rebalancing Strategic Workplan that brings together into one document the core components of the various plans. A "crosswalk" plan would highlight strategies to address key overlapping

components between and among the Plans, ascertain increased funding needs, and identify conflicts or strains on the systems resulting from roll-out of plans simultaneously. At the same time a comprehensive plan should not diminish the specific programs, activities and accountability designed to serve the discrete populations.

- *Build a Comprehensive Rebalancing Strategic Workplan to highlight strategies that address the overlapping demands on the systems: building service provider infrastructure and capacity; transition planning and implementation; housing development strategies; and coordination of Rebalancing and managed care implementation. Key partners and accountable entities responsible for implementation should be identified along with respective timeframes.*
- *Create a Rebalancing Financial Plan that identifies the current and projected resources allocated for Rebalancing within the State Budget by Department and Division, federal, and private and philanthropic resources. The Rebalancing Financial Plan will set the foundation to identify funding gaps and new resources essential for successful implementation. The Rebalancing Financial Plan should establish system goals such as proportion of Medicaid resources expended for community care, reporting on Section 811 and other federal resources, and create a mechanism to track cost off-sets and savings between programs/agencies that result from moving individuals from institutional care to community-based services. (Potential Model: IDoA Community Supportive Services FY-13 Budget Presentation and Rebalancing report detail required under PA 96-1501 Medicaid Reform Law.)*
- *Ensure input, coordination and accountability across Rebalancing Initiatives through expansion of the current Interagency Long-term Care Group or creation of other agency and stakeholder oversight body.*

**Delivery of Services in the Community**

**Recommendation 3:** Develop a plan to build community capacity and service delivery that outlines strategies to meet service and support needs of individuals with disabilities living in the community.

People with disabilities are able to live a quality life in the community when sufficient supports and coordination of care is available. Illinois has the benefit of a long standing and experienced community provider network. However despite this provider expertise, concerns exist about the current capacity (depth of service, geographic location, multiple diagnosis expertise, and availability of crisis care) of the network to meet the complex and comprehensive needs of the large number of individuals with disabilities moving under Rebalancing. Successful Rebalancing efforts rest on building the short and long-term capacity of these service providers in all areas of

the State and identifying the resources and flexible payment mechanisms to deliver increased and multiple services in smaller settings in the community.

- *Conduct a comprehensive survey of service capacity of providers across disabilities that identify common services delivered, staffing levels and credentials, and funding sources needed. The survey would also capture geographic coverage and unique services.*
- *Expand service delivery models, training curriculum and peer-to-peer networks that provide inter-disciplinary and cross-disability service, and enable maximum independence for individuals with disabilities.*
- *Develop and finance professional development, career ladder and earning opportunities for existing provider staff and longstanding staff of institutional settings transitioning their skills to community providers.*
- *Design and implement adequate reimbursement rates and flexible payment structures for complex service delivery in smaller community setting.*

**Building the Community-Based Housing Infrastructure**

**Recommendation 4:** Develop a strategic plan to clearly identify the housing needs and goals, the resource allocations, the accomplishments to date and gaps in the systems, and the strategies to fill the gaps across the Rebalancing Initiatives.

The State of Illinois has allocated capital resources for private and nonprofit developers to acquire, rehabilitate and construct community based housing for persons with disabilities moving from nursing facilities and intermediate care facilities. Partnerships are being formed with local and state governments and with public housing authorities to leverage additional units and rent subsidies. These strong efforts must continue and would benefit from a roadmap plan that can direct efforts and track achievements in meeting both the unit and affordability needs.

- *Identify target production goals for type of units with emphasis on non-segregated or four person or less homes, high demand geographic locations, physical accessibility, ownership/management structure, and realistic timelines.*
- *Build on comprehensive outreach and training for landlords, owner associations, community partners to foster understanding of Rebalancing goals, resources and service supports, and opportunities for partnership to expand existing private and public housing stock available for Rebalancing initiatives.*
- *Develop financial models that can leverage private and public resources for development of community based housing; reconfigure payment structure to enable increased development of small group homes; and maximize opportunities for rental assistance to increase affordability.*
- *Strengthen notification and referral system for units set-aside and/or accessible for persons with disabilities, and those relocating under the Rebalancing efforts.*

**Maximize Medicaid Flexibility**

**Recommendation 5:** The State and stakeholders should conduct, and report on, an analysis to determine benefits, costs and impact on Rebalancing of adopting and implementing enhancements to expand coverage and streamline payment processes under the existing and new home and community based service options for individuals transitioning under eligible Rebalancing Initiatives.

The Medicaid Program funded by the State and supported by federal match is a primary resource allocated to fund services and supports for Rebalancing Long-term Care in Illinois. Through the years (most recently in the Protection and Affordable Care Act of 2010, ACA) the federal Medicaid Program has implemented changes and advanced opportunities - through state plan options, waivers and incentive programs - for states to build flexibility enabling people with disabilities to receive long-term care services and supports in their homes and in a range of community residential care settings. Notwithstanding adoption of state plan options or waivers in Illinois, the Medicaid service taxonomy remains fragmented and inefficient for people with multiple disabilities and the providers that serve them. The SMART Act (PA 097-0689) passed by the Illinois legislature in 2012 states that its goal is to make changes to Medicaid in order stabilize the program for the future. Concerns have been raised about service coverage for persons in the community dependent on Medicaid support.

- *Identify opportunities to increase flexibility and coverage across disabilities and streamline provider billing processes across State Plan options and existing HCBS waivers. Determine whether the new long-term service and support options under ACA provide greater opportunities and resources for Rebalancing. Understand the offsetting detriments or costs associated with implementing these changes.*
- *Focus on the implications on Rebalancing of the Smart Act Medicaid program changes, with specific look at DON score thresholds and assessments, and service limits or reductions.*
- *Design and implement flexible payment structures for service delivery that maximize resources and blend service delivery based on the changes underway for Medicaid and managed care.*

**Coordinating Managed Care with Rebalancing**

**Recommendation 6:** State agency, managed care entities, and providers as identified by the State of Illinois must coordinate implementation of managed care to clearly demonstrate the roles and responsibilities, service components for individual coverage, and opportunities for improved outcomes created under coordinated care.

Rebalancing resources and services are managed by a variety of State agencies and community service providers based on specialty or disability expertise, resource requirements and historical structure. This "silo" infrastructure provides the benefits of specialized expertise and diverse philosophies of support, but also creates barriers to efficient and comprehensive service delivery for individuals transitioning under Rebalancing. The State is taking steps to break down these barriers through the implementation of integrated coordinated care.

The 2011 Illinois Medicaid Reform legislation (PA-96-1501) requires that by January 2015 at least 50% of all Medicaid clients be enrolled in a coordinated system of care and that payment systems for coordinated care be revised to disburse on performance based outcomes. With Medicaid as a primary resource supporting Rebalancing, the State's planned roll-out to a multi-phased coordinated care system intersects directly with Rebalancing efforts, requiring strong leadership, open communication, and investment in a broad range of community transition and support training and education for all participants. The State can utilize coordinated care initiatives, existing peer support systems, and Rebalancing to identify opportunities and training for providers to deliver a range of services for a single client or resident across disabilities, programs, and funding sources.

- *Create a detailed timeline of the roll-out of the multi-phased care coordination and how it aligns with each Rebalancing initiative. This timeline will also list the service/care options available to transitioning individuals at each phase of implementation along with the requirements for community providers to engage (operationally, fiscally, reporting) with the entities accountable for the health care network(s).*
- *Develop a "mutual education curriculum" to foster understanding and partnerships between managed care and community services and housing providers. This curriculum will cover eligibility requirements, enrollment processes, care coordination, and other case management services for individuals under Rebalancing.*
- *Maximize the opportunity available under the Illinois Care Coordination Innovations Project, and the new Coordinated Care Entities and Managed Care Community Networks to demonstrate and advance coordinated care for persons with disabilities transitioning to community settings from institutional care.*
- *Fully implement the unified budget mechanism that enables the transfer of funding for services between agencies to follow the resource needs of individuals transitioned from nursing facilities to community living.*

[i] *Olmstead v. L.C.*, 527 U.S. 581 (1999) is a U.S. Supreme Court decision in which the Court ruled that States were obligated to provide opportunities for persons with disabilities who choose to live in integrated and least restrictive community-based settings.

[ii] Contributing Workgroups and Reports: Williams Consent Decree Housing Focus Forum, IL Medicaid Advisory Long Term Care Subgroup, MFP Stakeholders Group, Facility Closure Legislative Workgroup, Care Coordination Stakeholders Group, Coleman Foundation Alternative Housing Group, Pierce Family Foundation Housing Group, Williams Court Monitor Interim Report to the Court, July 25, 2012, UIC College of Nursing Institute for Health Care Innovation *MFP 2009-2011 Year End Report*, CSH-HDA-SHPA, *Role of PSH in Implementing ACA and Medicaid Reform in IL*; NAMI-IL and SHPA, *IL State-Operated Facility Closure: Serving Dual Diagnoses of MI and DD*, and others.

***The Appendices I and II are provided for informational purposes and are not included as part of the Recommendations presented and approved by the Illinois Human Services Commission.***

## Appendix I - Additional Background Information on Rebalancing Initiatives

**Money Follows the Person (MFP**) – Money Follows the Person is a federal program providing financial incentive through enhanced Medicaid match to move from institutional care to community care models. The enhanced match is available from the federal government for 12 months following transition to community based living. Many of the costs associated with the transition of residents are eligible for reimbursement under Medicaid and the enhanced match. Transitions from other Rebalancing Initiatives will often overlap with MFP.

**Olmstead Court Decrees –** In 1999, the Supreme Court ruled under the Olmstead Decision that States had an obligation to provide reasonable choice for community living for persons with disabilities and elderly confined in nursing homes or other institutions. Since the Olmstead Decision, Illinois has settled three lawsuits (differentiated by the population and type of facility) which mandate the State move forward with diligence to provide opportunity for community living and services for class members.

*Williams* **–** The Williams Consent Decree includes an estimated 4500 persons with mental illness living in Institutes of Mental Disease (IMDs). Geographically the IMDs in Illinois are concentrated in the Chicago metropolitan area; with additional locations in Decatur, Peoria, and Kankakee. The Williams Consent Decree and Implementation Plan approved by the Court calls for full implementation over a five year period beginning in July 2011. *Ligas* – The Ligas Consent Decree mandates the State of Illinois provide opportunity to move and receive services in community settings for 100% of persons with developmental disabilities living in Intermediate Care Facilities for persons with Developmental Disabilities (ICF/DD) statewide that choose to move; and for new service provision for an estimated 3,000 individuals living in family homes. The total population in the family homes awaiting services is significantly greater. The time frame for implementation of the Ligas Decree is six years. All Class Members still living in family homes after six years who are seeking community services shall move off the waiting list at a "reasonable pace" to received community services.

*Colbert* – The Colbert Consent Decree requires the State of Illinois to provide opportunity for residents in skilled nursing facilities in Cook County to move to community-based living. Colbert class members include people who have mental illness, physical disabilities, and elderly. Approximately 16,000-17,000 residents could be impacted by the Colbert Consent Decree. Recognizing the magnitude of this effort, the Colbert Decree sets a timeframe of 30 months for the State to complete initial transitions of 1100 individuals. Based

upon that experience, the parties will develop a "cost neutral" assessment and plan to move the remainder of the class members who wish to move to the community while limiting the State's spending to no more in aggregate than it is spending for their care in nursing facilities.

**State Facility Closures** – In January 2012, Governor Pat Quinn announced plans to begin closure of certain State operated developmental centers (SODC) and psychiatric hospitals (SOPH). The plan seeks to enhance the quality of life of residents in the same vein as the Olmstead principles, but also to achieve costs savings through the closure of antiquated facilities. At least four facilities were identified for closure initially including Jacksonville Developmental Center in west central IL, Tinley Park Psychiatric Hospital in metro Chicago, Murray Developmental Center in southwest IL, and Singer Center in the Rockford area.

## Appendix II - Detailed Issues and Actions from Various Rebalancing Workgroups and Reports

The following four charts incorporate many of the issues and recommended actions identified by various rebalancing and system change reports and workgroups. These charts provide a foundation for continued discussion by the HSC Rebalancing Workgroup:

*Transition Process*

Multi-step process to successfully transition residents to community based settings and services: Outreach, Assessment, Transition Planning and Implementation, Care Management and Monitoring.

The University of Illinois at Chicago School of Nursing Institute for Health Care Innovation recently released a report on the enrollment of 709, and transition of over 475 individuals under MFP for the period 2009-2011; specifically looking at those individuals that transitioned early, have remained in the community for over one year, or have experienced critical incidents. The central recommendations from the Report and from subsequent discussions focused on opportunities to:

| ***Transition Issues*** | ***Action*** |
|---|---|
| Increase enrollment in MFP and other Rebalancing Initiatives | Broader referral networks, improved coordination with nursing home providers, follow-up contact with residents who initially decline consideration<br><br>Clear and repeated communication of information for individuals (and their family or guardians) regarding choices to assure informed and authorized decisions<br><br>Build and expand current coordination through the Aging and Disability Resource Centers, and other community representatives |

| | |
|---|---|
| Enhanced training for Transition Coordinators | Assessment skills, behavioral indicators, Medicaid/Medicare services and providers, resources in the community<br><br>Delineation of the responsibilities of the transition coordinators from the responsibilities more appropriately assigned to healthcare providers |
| Complex medical needs and dual diagnoses | Create integrated care management and broaden skills of the staffing teams |
| Improve transition sustainability | Identify resident specific risk mitigation needs in the service plan with specific follow-up protocol. Increase follow-up and monitoring of transitioned individuals while maintaining values of choice and self-determination |
| Improve Participant Self-management | Provide training for individuals pre and post transition on medicine management, life skills, service providers and 24 hr. back-up plan<br><br>Deploy resources for skill development and supports for individuals both in nursing facilities (pre-transition) and in the community |

*Community-Based Housing*

The type of independent permanent housing deemed appropriate for an individual is based on a number of factors including: the choice of the individual, the desired geography, the degree of care or services needed by the individual to maintain independent living, and the affordability of the housing. In general community-based settings can range from scattered site apartments and homes, to site-based supportive housing, to small residential supervised settings depending on the needs and desires of the individual. Certain mandated restrictions related to concentration of the targeted populations in a type of housing deemed sufficiently independent or non-institutional are outlined in the Rebalancing Initiatives.

| *Housing Issue:* | *Action* | *Action* |
|---|---|---|
| Minimize concentrations of persons with disabilities in single properties | Incentivize unit set asides within affordable housing developments<br><br>Maximize site-based supportive housing that maintains rights of tenancy and independence with supports | Expand master lease models to scattered site units |
| Increase affordability for residents on limited SSI/SSDI income (<$700month) | Opportunities for rent subsidies: Section 811 program, Rental Housing Support, DMH Bridge subsidy, HOME funds, and partnerships with public housing authorities for vouchers and project based vouchers | Use capital and operating resources to write-down unit rent to 15% AMI ($8,000) |
| Economic stability for CILA homes at 4 beds or less | Adjust pay rate and payment timing to improve operational economics for 4 bed CILAs | |
| Identify units in market place | Increase capability of ILhousingsearch.org: secure case manager page; mandatory listings for subsidized housing; marketing and outreach to property owners<br><br>Identify vacant units in bank owned foreclosed properties, existing affordable developments and public housing inventory<br><br>Target unit identification in high demand areas and build service network in areas with housing availability | Expand IFF/Access Living model of long-term property ownership for persons with disabilities<br><br>Foster relationship between property management and service provider: workshop on service packages, good neighbor practices, and crisis management<br><br>Explore technology supports to advance independent living<br><br>Provide funding support for transition coordinators to locate housing |
| Quality of housing stock | Streamline inspection process and provide training for property owners | Partner with local CD programs to identify rehabilitated homes |

| | | |
|---|---|---|
| Need for new unit creation through construction or rehabilitation | Develop RFP that "braids" resources for housing development and set-asides | Identify high need areas for new development |
| At-risk populations require higher level of monitoring | Incorporate skilled mental health and medical staff to on-site teams | Develop specialized housing and supervised monitoring for high risk individuals |
| Alternative housing models that promote independence for residents | Scattered site rental by experienced service providers<br><br>Independent roommate homes with available services | Joint tenancy ownership of group homes by families of persons with disabilities |

*Delivery of Services in the Community*

Significant concerns have been raised about the capacity of the network of community agencies to meet the complex and comprehensive needs of residents transitioned under Rebalancing.

| ***Service Issues:*** | ***Action*** | ***Action*** |
|---|---|---|
| Improve communication and information sharing | Launch comprehensive outreach campaign for residents, family, providers and community using media, technology and in-person methods<br><br>Coordinate outreach within facilities to minimize confusion caused my multiple contacts | Improve transfer information gained in assessment and transition to service providers<br><br>Create peer-to-peer education and networks for providers, residents and families |
| Complex health and service needs for individuals transitioning will require efficiencies in service delivery | Implement comprehensive service models - higher level including: Psych, med admin, case mgmt, crisis intervention, risk mitigation, behavioral analysis<br><br>Develop levels of supervised monitoring for complex and high risk individuals | Implement a Technical Assistance Center for providers and transition coordinators to learn best practices and foster innovation<br><br>Explore technology supports to advance independence |

| | | |
|---|---|---|
| Community capacity is deficient in specific skills and geographic availability to service transitioning populations | Conduct and document a comprehensive survey of service capacity across the disability and service community<br><br>Workforce training and career development to redeploy employees from state facility closures | Develop training modules for service delivery deficiencies including dental care, crisis networks.<br><br>Utilize institutional care as part of short-term safety net, with specific individual plans to return the individual to the community<br><br>Identify gaps in geography and target training for providers |
| Dual role of housing provider and service provider | Develop a "curriculum for change" training for CILA providers to facilitate the service choice for residents<br><br>Separate housing funding from service funding to create greater choice for residents | Support demonstration program for group homes held by unrelated third party; with focus on quality care |
| Improve transition sustainability | Improve monitoring and tracking of outcomes<br><br>Develop models to assess and implement service change needs for residents over time<br><br>Expand service package to include social and employment services | Allow for movement to alternate housing settings to accommodate changing needs and relationships<br><br>Simplify "transition fund" procedures |

*Financial Resources*

Rebalancing Long-term Care is not only about moving people from institutional to community settings, but it requires significant redirecting and new resources to support the movement to community. The State of Illinois' current fiscal crisis places enormous pressures on the Rebalancing efforts. Simultaneously the movements to managed and coordinated care create opportunities to more effectively address the comprehensive needs of persons with disabilities living in the community.

| *Resource Issues* | *Action* | *Action* |
|---|---|---|
| FY 13 Budget constraints on community based service delivery | Identify all line items across state agencies that support rebalancing | Permit bundling or other payment coordination of services across budget line items |
| Smart Act spending reductions in Medicaid may impact coverage for residents transitioning under Rebalancing | Implement Cook County Medicaid waiver<br><br>Expand HCBS waivers to enhance coverage for rebalancing residents | Begin Medicaid qualifications as soon as eligible for residents transitioned under Williams<br><br>Examine waiver of Medicaid spend-down requirements for individuals transitioning under Rebalancing |
| Billing systems for individual services are complex | Restructure rates as single day or bundled pay rates vs. individual service rates<br><br>Coordinate Medicaid claiming systems between and among state agencies and qualified community providers | Use Coordinated Care Innovations Project models to demonstrate efficient payment across multiple service needs and providers<br><br>Implement system for federal funds match to be invested in programs that support Rebalancing |
| Delayed payment to community providers | Identify strategies to resolve payment delays including advances and priority payments | |
| Move 50% of eligible Medicaid recipients to Managed and Coordinated Care by 2015 | Incorporate Rebalancing individuals in Coordinated Care Innovations Projects | Outreach to Managed Care agencies to develop plans for Rebalancing individuals |
| Identify resources post 12 month enhanced federal match under MFP. | Investigate "Critical time intervention" (CTI) model developed by Housing Solutions to reduce service needs after initial transition | |
| Rebalancing service taxonomy includes components eligible, but not currently covered by Medicaid | Implement billing process and if necessary Medicaid waiver to cover employment services, supportive housing case management, training, and other related expenses | |

**Illinois Human Services Commission**
**Workgroup on Rebalancing Long-term Care**
**MINORITY REPORT**
**From AFSCME Council 31**

The process of creating the Rebalancing Workgroup report has resulted in some meaningful discussion of controversial issues. What has not resulted is a clear statement of the challenges ahead as the Quinn Administration seeks to radically alter the service delivery system for individuals with disabilities. Such clarity is urgently needed, especially by those individuals whose very lives depend upon essential supports. Moving forward without addressing these challenges will bring change, but it will not improve lives and outcomes, and may place some lives at risk.

*One person's "institution" is another person's home

The report underlines the right of individuals and guardians to choose congregate settings over community group homes or apartments, as provided for in recent consent decrees such as Williams and Ligas. However, by using what has generally become a pejorative term--"institution"--for those congregate settings, the document diminishes those who prefer the safety, enhanced services and social interaction provided by such settings and sets the stage for those who advocate for prohibiting this ability to choose.

*The pace of change

While the report highlights the desire to be planful, respectful of choice and person-centered during any transition, the real-world process of closures and downsizing that the Quinn administration is now undertaking is light years away from such elevated concepts. The Jacksonville Developmental Center closure has been characterized by disorder and confusion. Many families have been offered only one "choice" of community placement for their loved ones—and often it would weaken family ties by moving the individual to other regions of the state. In many instances the families do not feel that the placement would meet their loved ones complex medical and behavioral needs, but they are under intense pressure to agree to these moves because they have been told the center will close on Nov. 21, and they could find themselves left without any services at all. Some settings that have accepted individuals from JDC with high need levels have no record providing these services, and that has already resulted in some of the individuals becoming police involved or hospitalized. Individuals are being moved 10 and 15 on a given day, driven off in buses, giving the impression of a forced exodus. In sum, the rapid pace of the JDC closure is not planful, respectful of choice or person-centered.

*Outcome measures, data sharing and creating good outcomes

The report largely presumes that rebalancing will always result in positive outcomes. It does state that all outcome data – both positive and negative – should be communicated. Yet the commitment made by Mark Doyle, the Governor's rebalancing officer, to share data from the Tinley Park Mental Health Center closure has still not been fulfilled. And the Singer Mental Health Center closure proceeded without the public benefitting from the information contained in that outcome data. Refusing to share this information at a minimum casts doubt on whether those rebalancing initiatives actually were positive—and raises questions as to whether data will be fully shared going forward.

*The impact on direct support employees' compensation and implications for quality care

While there was substantial debate about whether rebalancing would yield positive outcomes in all cases for the affected individuals with disabilities, there can be no doubt about the impact on employee wages and benefits. The state has consistently underfunded community agencies—with the result that even the most well-established providers are not able to pay a living wage, while many marginal providers pay little more than the minimum wage. In many instances, these workers are not provided with affordable health insurance, nor do they have any form of retirement benefit. In other words, rebalancing is actually being balanced on the backs of the thousands of dedicated direct support workers who provide essential care, support and services to individuals with disabilities. The constant refrain of "cheaper in the community" is really no more than a euphemism for workforce injustice. Employees at state centers earn fair wages and benefits. Governor Quinn's rebalancing initiative is deliberately seeking to replace those family-sustaining jobs with low-wage, no-benefit positions in community settings and force employees to accept that lower standard of living. This chronic underfunding of the direct care workforce in the community—a workforce upon whom ever-increasing demands will be made as part of the rebalancing initiative--has serious implications for quality and consistency of care, as low wages are among the strongest predictors for high turnover which in turn is a critical variable in determining qualify of services.

*Independence is not always possible

The disadvantage of creating a report that speaks to so many people with so many different kinds of challenges is that what works well for one may or may not work well for another. That is where the language of choice is important. There is problematic language in the report which speaks to the need of individuals with disabilities to "manage responsibilities of independent living". While this is a positive goal for many individuals, we are concerned this assertion could be used as justification to abandon those who now and in the future will require ongoing and comprehensive supports and services. The individuals for whom these supports are most critical are also those who incur the greatest expenses for our state. By tying the rhetoric of independence and

responsibility to economic efficiency, we are concerned the report may lay the political groundwork for neglecting those who have the greatest need.

**Illinois Human Services Commission**
**Workgroup on Rebalancing Long-term Care**
**MINORITY REPORT**
**From William Choslovsky**

To be clear, the Working Group Report is well intended. My fellow commissioners worked hard. I presume their hearts are in the right place.

But good intentions aside, the report is flawed in several respects.

First, as a general matter, its focus – if not obsession – with "institutions" is misplaced. The first sentence of the report sets the tone by focusing on people "moving out of institutional settings." Although the Report uses the word "institutions" about twenty times, it never defines what an "institution" is. Likewise, there is no showing that most individuals (and their families) now living in "institutions" actually have any desire to move. In short, for many their "choice" is an "institution." Moreover, focusing on semantics – "institution" versus "community" – is counterproductive. The labels are more destructive and divisive than descriptive. One person's "institution" is another person's "home." Defining an "institution" as something with eight beds, or six beds, or four beds is equal parts artificial and arbitrary. Quality of care or choice should not be defined by just one metric: size. Though I could provide examples or statistics of substandard care in the "community," the goal is not to pit "community" providers against "institutional" providers, as both have a place. Instead, Misericordia's Sister Rosemary Connelly sums up the "issue" best when she says: "Big can be bad; small can be bad; both can be good. When it comes to caring for the developmentally disabled, one size does not fit all and true choice is a two way street."[ii]

Second, the paramount factor (or metric) for determining where someone lives should, of course, be his or her (or the guardian's) *choice.* The Report does a good job of expressing this principle.

Third, if the issue is money – because the state is effectively broke – then we should honestly acknowledge that, as opposed to cloaking the issue as something else like quality of care or choice. For instance, the state's remaining eight centers (SODCs) that care for approximately 2000 developmentally disabled individuals are costly. Specifically, according to published reports, the average cost per resident is approximately $150,000. In contrast, the approximate cost for someone who lives in a *private* "institution" (ICF-DD) *or* a "community" home (CILA) is actually about the same, roughly $50,000-$60,000. Although the choice for many residents (and their families) now living in SODCs is to remain in their SODC, if, for fiscal reasons, such a choice is no

longer tenable, then the state should state as such rather than suggest that the residents are receiving suboptimal care or that such is not their choice.

Fourth, expanding *choice* for some should not come at the expense of eliminating *choice* for others. Likewise, robbing Peter (institutions) to pay Paul ("community" options) ultimately provides a false *choice*.

Fifth, whenever possible, recommendations should be specifically tailored to the different populations. That is, what may work for a mentally ill (MI) individual may not work for a developmentally disabled (DD) individual. They are discrete populations, and of course, within each population each individual is different. Thus, "one stop shopping" does not work.

Sixth, the focus should be more on the individual, and less on the "system." That is, most families and those who need services don't know or care about acronyms or various agency categories. Likewise, they don't care whether the bureaucrats score something as an "ICF" or a "CILA," so long as it provides the care they need. Instead they, of course, simply want services that suit their needs. As I understand it, the gatekeeper for most populations – e.g., DD & MI – to receive services is a PAS agency, yet PAS agencies are not discussed in the Report. The Report should direct that when an eligible person requests services, she should be given a "menu" of sorts explaining all of her options (i.e., CILA, ICF, SODC, at home) from the PAS agency. Likewise, PAS agencies should not steer people toward any one service choice, but instead should present all service options. PAS agencies should be ombudsmen of sorts, not surrogates or advocates for a certain type of service option. Ultimately, this circles back to the guiding principle of *choice*, which *choice* belongs to an individual (or guardian) and not to a PAS agency or state bureaucrat pushing a favored agenda.

Seventh, for those individuals moved from "institutions" to the "community" – and especially those moved from SODCs when closed – the state should publicly report no less than annually on the status and progress of the moved individuals. This is especially so since it has been reported that often death rates *increase* for residents when moved from "institutions" to the "community."

All said, the Report does much good, but in focusing on divisive labels like "institution" and lacking specifics on funding, it falls a bit short. I appreciate the opportunity to have participated in this process.

November 2, 2012

Respectively,

William Choslovsky

**Illinois Human Services Commission**
**Workgroup on Rebalancing Long-term Care**
**MINORITY REPORT**
**From Shawn Jeffers**

***"All that is necessary for the triumph of evil is that good men and women do nothing" - Martin Luther King***

I want to go on record as in support of the "minority report" submitted by William "Bill" Choslovsky, Esq. I am particularly concerned by the syllogism applied to the concept of "institution or institutional settings" as stated or inferred throughout the proposed rebalancing report. In reading the report a viewer can reasonably conclude the following:

All institutions or institutional settings are "bad" (the major premise),
Organizations like Little City Foundation are institutions (the minor premise), therefore,
Organizations like Little City are bad, (the conclusion).

In an earlier meeting with the rebalancing committee, I asked that consideration be given to defining terms such as "community" and "institutions" but my suggestion was summarily dismissed. The opinion expressed by various committee members (except for the Chair) was akin to the idea that we already know what it is or would know it when we see it so there was no need for definitions i.e., "community or institutions". While I disagreed with this premise I chose not to continue to push the issue in the interest of time. After reading the report I regret relenting on this important distinction.

The rebalancing report starts out with the following declaration: "Rebalancing Long-term Care in Illinois is a broad effort by the State to provide opportunity for persons with disabilities and seniors to choose to live in appropriate integrated settings in the community; moving out of institutional settings." Are organizations like Little City Foundation, Misericordia or Marklund the next targets of rebalancing? Is the goal of rebalancing a license to remove people from settings such as Little City Foundation, Misericordia, Marklund and similar campus-based programs and not make it a "choice" option for individuals and their families? The answer seems obvious to me now, and it is on this basis that I enter an objection.

Up to this point, my organization made a conscious but difficult decision to stay out of the fray. The issues being debated – closing of under-performing or under-funded state-operated developmental centers or the closing of large poorly operated ICF-DDs – was not actions that our constituency were particularly indifferent to. I recall that during my initial meeting with Bill Choslovsky he asked why Little City Foundation was silent on the issue and I explained how our residential service and program mix did not include ICF-DD offerings or other options previously under attack.

The recent exchange between Bill and others on the distribution list really disturbed me as the arm of attack has clearly moved into my organization's backyard. I have consulted with others in our organization, most importantly the individuals we faithfully serve and their families, and they want us to be their voice on this issue. In taking our position I am reminded of a famous statement attributed to Pastor Martin Niemöller (1892–1984) about the inactivity of German intellectuals following the Nazi rise to power and the systematic eradication of their chosen aims, group after group. As a refresher here is a rendition of the text:

"First they came for the socialists, and I didn't speak out because I wasn't a socialist.

Then they came for the trade unionists, and I didn't speak out because I wasn't a trade unionist.

Then they came for the Jews, and I didn't speak out because I wasn't a Jew.

Then they came for me, and there was no one left to speak for me."

I realize that for some self-proclaimed "advocates" the organization I lead (Little City Foundation) is among their targets for abolition despite our being a preferred choice for so many people. I am concerned that if the true advocates of choice do not speak up and speak out there really will not be any choices except for those options that the arbiters of opinion feel are appropriate. At some point I hope that the voices of the families we serve and the individuals we support are heard and that more respect is given to their "CHOICE". I have grown tired of hearing these individuals and their families being marginalized and described as ill-informed, out of touch, uncaring, duped etc. for choosing to forego options outside of what they presently have, i.e., campus-based living.

For over 53 years, Little City Foundation has served as the supportive home for hundreds of children and adults with intellectual and developmental disabilities. Our array of residential living

and family support options range from providing supports in private homes, CILA, SLA, and CLF. We have a continuum of options that are uniquely positioned and made available to afford individuals with choices for how and where to live based on the dynamic nature of their life cycle. We have never and will never hold an individual or family hostage to our program and we commit ourselves to helping people and their families find the best option for them (even if it includes leaving our organization). Call us what you want –institution or otherwise – but make sure that the definition used truly captures the essence of who and what we are, as described by the people who entrust us with their care.

I hope that the HSC Rebalancing Workgroup report, once amended, edited etc., gives more transparency and clarity particularly in its definition and descriptions of terms. I hope that the report clearly states a position on "institutions" or clarifies what it means by the use of this term. By doing so the many parents and families who entrust us with the care of their loved ones; the individuals who seek our help to achieve a meaningful and fulfilling life; the legion of donors and volunteers who believe in and invest in our mission; and the staff who each day dedicate their heart and soul to pursuit of mission will more clearly know who stands with them on the issues important to them – respect for and acceptance of their "choice".

In preparing my remarks I gave our parents and advocates a chance to review what I had written and asked if I appropriately and accurately conveyed their feelings. I want share a direct comment I received from the parent of a young man who resides in one of our campus-based homes, she writes: It sounds great to me—no edits to recommend. I will add that it appears to me that the so-called advocates are taking advantage of the closing of state ops and trying to sneak in their ultimate desire to close anything they think looks like an institution by cleverly manipulating the language. It is devious and despicable—and I resent anyone denigrating my choice without truly having knowledge of the choice I made or the reasons I made it!"

In support of this parent and other stakeholders I end with the following:

May those that love us, love us.
For those that don't love us,
May God turn their hearts.
And if he doesn't turn their hearts,
May he turn their ankles,
So we'll know them by their limping.

- Irish toast

Respectfully submitted…